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ABSTRACT

Hospice care (health care for the terminally ill that emphasizes emotional support for the patient and family) is essential to ease emotional, psychological, and social pain, and can be a factor in addressing spiritual and physical pain. Yet to ease the pain of final illness, therapeutic communication must extend beyond words. Physical contact--in the form of reassuring, affirming touch--is essential in addressing the psychological pain of a hospice patient. The relief of psychological or emotional pain is also dependent on the environment where communication occurs. The philosophy of all hospices is that patients should remain in their own home as long as possible. However, when patients need to leave their homes, the hospice environment should be essentially different from a hospital, with designs to include maximum natural lighting, fireplaces, wood-paneled ceilings, small gardens, and common entrances for patients, staff, and families. Personal objects are also important in a hospice room, where they preserve self-definition against the threat of institutional uniformity. Photographs, books, antiques, throw rugs, and pets are not just surface pleasantries, but are ways of sustaining and expressing the person who is more than a body. Scholars of nonverbal behavior can be helpful to the hospice movement by learning from professional and lay care-givers who have intuitively incorporated nonverbal communication into their efforts. Patients themselves are also valuable sources of insight. (MM)

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Nonverbal Communication in Hospice Care

There is a line in Dante's Inferno which reads: "In the middle of the journey of my life I came to myself in a dark wood where the straight way was lost." Every human life is indeed a journey through time, and the traveler knows that unexpected darkness may fall in the form of illness and death. But death is usually not as frightening as the prospect of losing one's way in the face of it, of ending the journey in meaningless pain without identity or dignity. Out of respect for the journey of life and the darkness which threatens it has come the concept of hospice.

From its beginning the hospice movement has involved important symbolic aspects. The language by which hospice describes itself guides its aspirations and priorities, and is particularly important in contrast to nursing homes and hospitals which increasingly refer to themselves as "industries." The term "hospice" derives from the way-stations which were established for pilgrims in the middle ages. Hospices provided places to rest and friends who honored the importance of the traveler's journey. Thus the pilgrim could complete the journey without straying from the way or becoming lost in Dante's dark wood. When Dr. Cicely Saunders founded St. Christopher's Hospice in London in 1967, she renewed the medieval concept of hospice and added the name of the travelers' saint. St. Christopher's Hospice, and the hundreds of programs it inspired, have been created as way-stations for the dying, in the belief that every step of the journey is important and should not be darkened by pain, loneliness, and loss of self-identity.

Moreover these are "mobile" way stations which can meet the traveler wherever he/she needs to rest. St. Christopher's, St. Joseph's, and St. Luke's Hospices in England are specialized permanent facilities for the terminally ill, but their services and information extend far beyond their

walls. Hospice services in the United States are most often provided in the patient's home, with wings of some hospitals designated as auxiliary hospice units. These physical variations serve to underscore that hospice is not a place but a philosophy. Thus we speak of "hospice" instead of "a hospice."

With these brief historical and symbolic considerations in mind, this paper will suggest that the communication aspect of hospice care is essential to easing three kinds of pain: emotional, psychological, and social; and is a factor in addressing spiritual and physical pain. But if it is to ease the pain of final illness, therapeutic communication must extend beyond words.

Communication Beyond Words

Those who understand crisis communication know that death cannot be addressed with verbal clichés. The friend of a woman who died in a traditional hospital setting offers this reminder of the limits of words:

> When Eleanor opened her eyes for a moment and saw me sitting by the bed, she reached toward me. "I'm afraid," she whispered. I didn't know how to respond, so as soon as the day nurse came in, I asked her advice. "You'd better ask the doctor," the day nurse said. The doctor didn't come, so I went to the night nurse when she arrived. "What can you say?" the night nurse murmured, patting my arm. "You should call the chaplain. Let him reassure her." Eleanor did not believe in churches or chaplains, so I asked the resident when he came by on his rounds. "You have to give her some supportive psychotherapy," he said. "Just tell her there's nothing to be afraid of." I didn't agree, and when her doctor appeared, I asked him. He looked troubled and a little

> embarrassed. "Tell her . . . tell her she's apprehensive." A little student nurse looked in at the door . . . and, cruelly, I asked her: "What should I say when she tells me she's afraid?" The little nurse bent her head quickly and stared at the tips of her shoes. "Aw gee," she said softly. She raised her head and looked at me, her eyes gleaming with tears. "Aw gee," she said again. Here, at last, was an answer I could understand. [1]

The inadequacy of words in times of extremity should lead us to seek other forms of communication. Susanne K. Langer wrote of finding the right symbolic form in each particular instance to convey the intended thought or feeling. [2] These symbolic possibilities always include more than words, but the intensity of terminal illness and the inadequacy or loss of verbal abilities make urgent the search for alternative communciation. Thus the warmed bed awaiting a patient who enters St. Christopher's Hospice and the natural light from its massive banks of windows are not products of public relations strategy or architectural whim, but conscious symbols which communicate concern and affirmation.

In an American hospice, a social worker may be found encouraging a child to draw a picture for his dying mother, while his father prepares gelatin that she can still swallow or rubs her hands with scented cream. [3] Clinical observations indicate that such communication does reach a patient, and also allows a family to feel less helpless at the moment and less guilty later; the latter conclusion is confirmed by studies comparing the mourning process of widows who cared for their spouses with widows who did not. [4] As always, the healthiest communication serves mutual needs, and crisis communication should escalate rather than abandon this mutuality.

Physical contact--in the form of reassuring, affirming touch--is essential in addressing the psychological pain of a hospice patient. Lewis Thomas,

Chancellor of Sloan-Kettering Cancer Center in New York, writes that the essence of doctoring was once the art of touching, and in the absence of sophisticated drugs and equipment, only those who were comfortable in giving such touch selected medicine as a profession. [5] Today, sophisticated medical technology can allow doctors to maintain a physical distance from patients; and laymen who are already inhibited by our cultural uneasiness toward touch are often restrained in extending physical affection to a dying person. Thomas acknowledges that "some people don't like being handled by others, but not, or almost never, sick people. They need to be touched, and part of the dismay in being very sick is the lack of close human contact." [6] Many patients fear that they appear repulsive in light of weight loss or other physical deterioration. To address this social pain, family members and hospice personnel must physically express their unqualified acceptance; and sometimes they must compensate for the distance maintained by medical personnel during earlier stages of treatment. Those who join hospice as associated clergy, social workers, nurses, and patient care volunteers must be comfortable with physical contact, and thus practice the self-selection that was exercised by doctors a century ago. This will be extremely important in coming months as hospice services are increasingly extended to victims of AIDS. One certainty about AIDS is that it is not spread by surface body contact. Those who would withhold reassuring, comforting, respectful touch out of misplaced fear have no place as hospice personnel.

Saunders describes the awareness that St. Christopher's Hospice shows toward the tactile and other sensory needs of a patient, and suggests that these vital senses provide a final avenue of communication. She writes:

> Over the years of caring for the dying we have learned that, although thirst may be the last craving, there are many more acceptable ways of easing it than intravenous drips; many flavors, including whiskey, may be added to ice cubes. Hearing and touch

> are the last senses to go. When death is imminent . . . the patient . . . may still be hearing . . . and be somehow aware of . . . [the family's] presence. I am sometimes asked: "Is it really worthwhile my being here? Does he know I am here?" To me, the answer is an analogy to a married person who doesn't sleep as well when the partner is away. He, or she, will not be awake all night, but something in the sleep is more comfortable when the person is there. [7]

Through a responsive presence which extends beyond words, a care-giver or family member may break through to the level that Martin Buber once described as a "wordless-being-with-one-another." [8]

Proxemic Considerations

If emotional and psychological pain are to be eased through nonverbal communication, such relief is often dependent on the environment where the communication occurs. Drawing in part from research by environmental psychologists, the study of nonverbal behavior usually includes attention to proxemics--the ways in which space is used and how those uses affect human attitudes and interaction.

The philosophy of all hospices, including the specialized care centers in Britain, is that a patient should remain in his/her own home as long as possible. The self-control and self-identity which are possible in one's own home cannot be duplicated even in the best of institutions, and leaving one's own place is an additional kind of pain. Thus, a large number of hospice patients remain at home until death--with all hospice services brought to them.

However, when patients do need to leave their homes, the hospice

environment should be essentially different from a hospital. The designer of the Connecticut Hospice speaks of an "architecture of healing," which he emphasizes is much different from a design for curing. [9] Hospice designs often include maximum natural lighting, fireplaces, wood-paneled ceilings, lounge and patio areas, small gardens, chapels, common entrances for patients, staff, and families--and sometimes built-in day care centers for children of the staff "permitting children to see the . . . patients and the patients to see children, reminders that neither group exists in a world without the other." [10] The District of Columbia Hospice is not unusual in its brightly colored furniture, coffee pots steaming in kitchenettes, and large picture windows. Saunders believes beauty is healing; being able to look out on trees "makes patients see that the creation to which they belong is good--it can be trusted." [11] Even a converted hospital wing, as used by Cedar Valley Hospice in Iowa, can be substantially altered by painting the walls in light colors, installing different draperies in every room, and using table lamps instead of overhead lighting. These environmental factors must be vigorously pursued as integral to the hospice approach in order to resist institutional drift toward standarization and bulk purchasing. [12]

Research in nonverbal communication and environmental psychology also underscores the importance of personal objects in the preservation of self-identity. [13] Such "artifacts" can individualize a dormitory or even a motel room, and Margaret Mead once described their importance to a person whose only space was a berth during a sea voyage. [14] But nowhere are personal objects as important as in a hospice room, where they preserve self-definition against the threat of institutional uniformity.

Eric J. Cassell, of Cornell University Medical College, writes that suffering occurs in both body and mind, and traditional medicine too often

focuses on the body while allowing "destruction of the person." In his distinction between "bodies" and "persons," he writes that a person has an individual history, a cultural background, and roles which define his/her life in relation to others. [15] Indifference to this life of the mind and the objects which symbolize it constitutes destruction of identity.

Unlike a hospital room, where space is filled with objects needed by medical personnel to attend the body, a hospice room should be a place where the patient's objects identify his/her ousia--the wholeness of a life which encompasses far more than a last illness. [16] Thus photographs, books, antiques, throw rugs, quilts, even pets, which are found in hospice rooms are not surface pleasantries, but are ways of sustaining and expressing the person who is more than a body. A patient serving her own wine to guests at Iowa's Cedar Valley Hospice and a patient-artist hosting an exhibition of his work at the Connecticut Hospice are affirming their own identities through the objects they value. To be surrounded by personal artifacts may also be a way of coming to terms with one's own life history--allowing a peace of mind which puts to rest one kind of suffering. [17]

Conclusion

Scholars of nonverbal behavior can be helpful to the hospice movement by learning from professional and lay care-givers who have intuitively incorporated nonverbal communication into their efforts. The wisdom of their experience can be recorded, and occasionally enlarged, by communication researchers--and then returned to the care-givers for their further application.

Perhaps the most important source of insight comes from the patients themselves. Hospice personnel frequently confirm the truths they learn from people who are living even as they die. Such insight has been captured

in A Reckoning, a remarkable novel by May Sarton, written from the point of view of a dying woman. From the mind of this woman, we learn that words no longer address her needs--but she can still respond to the texture and scent of daffodils, the sound of quiet music, and the taste of champagne. [18] Both figuratively and literally, hospice strives to keep daffodils and champagne in the life of a dying person.

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